Virginia Arnold likes to plan ahead. With a family history of age-related macular degeneration (AMD), the 65-year old was determined to prepare for the possibility she also would develop the disease someday. “My grandmother had AMD and so did my mother and her siblings. I always figured I would have it too when I was in my 70s,” says Virginia, whose family is enrolled in the Genetics of AMD Study at Casey Eye Institute’s Macular Degeneration Center.

To her surprise, however, doctors found the beginning stages of AMD when she was only 62. “I was completely shocked. This was not in my plan at all — I was off schedule by 10 years,” says Virginia, who lives in a small town outside of Salem, Oregon.

As a result of her diagnosis, Virginia wanted to learn more about her condition so she could make informed decisions about the future, such as retirement and housing. What were her chances of developing advanced AMD? And how quickly?

For help with these questions, Virginia turned to Michael Klein, M.D., director of Casey Eye Institute’s Macular Degeneration Center and a pioneer in genetic research of AMD. Dr. Klein and his team are conducting groundbreaking investigations to solve the genetic puzzle of AMD. As part of their work, Dr. Klein and his colleagues have crafted an online tool that enables eye doctors to calculate a patient’s likelihood of developing the vision-affecting advanced form of AMD, the type of advanced AMD and when that progression might occur. Their report about the model was published in the December 2011 issue of the Archives of Ophthalmology.

Using Casey’s new risk calculator, it is estimated that Virginia has a 25 percent chance of developing advanced macular degeneration in either eye in five years.
Disease Study (AREDS), a multi-center clinical trial conducted from 1990 to 2001. The information included participants’ DNA samples, medical and ocular history, and results of a retina examination by a study ophthalmologist.

The risk calculator, available on the Casey Eye Institute Web site, is intended to be used by eye doctors for patients between the ages of 55 and 80. It combines findings from an eye examination (including evaluation of the retina) with a medical history that includes age, family history of AMD, and smoking history. Genetic information, comprised of the two most common known gene variants linked to AMD, may also be included in the calculation. However, this is not a necessary component and the risk calculator is designed for use with or without this information.

“Having this information can help guide patients in taking certain precautions and adopting preventive measures. These include frequency of eye examinations, monitoring central vision at home, healthy lifestyle changes, and taking nutritional supplements,” says Dr. Klein.

As progress accelerates in developing new and more effective methods of prevention and early treatment of AMD, the ability to accurately predict who is most likely to progress from early to advanced AMD with vision loss will become even more important, says Dr. Klein.

The researchers will update the model as more is discovered about the genetic and environmental influences on AMD, he adds.

Based on Virginia’s own risk factors, Dr. Klein estimated she has a 25 percent chance of developing advanced AMD in one eye in five years. Armed with this information, Virginia is starting new hobbies she can do even if her eyesight worsens. For example, she’s learning to weave from a woman with severe macular degeneration — a skill she’s longed to acquire. “She’s taught me some tricks to use if my vision declines, such as using high contrast patterns and special tools for threading,” says Virginia. She also is doing all she can to keep her eyes healthy. “I wear sunglasses to block out UV rays, eat lots of vegetables and exercise. I feel pretty prepared,” she says.

Co-authoring the report were Peter J Francis, M.D., Ph.D., Frederick L. Ferris, M.D. (National Eye Institute), Sara Hamon, Ph.D. (Rockefeller University), and Traci Clemons, Ph.D. (The Emmes Corporation).
Center’s Genetic Research Program Wins Major Grant

The Macular Degeneration Center recently was awarded a five-year grant of $2.5 million from the National Eye Institute to support further studies by Casey researchers of the genetics of macular degeneration. A major part of the research will involve collaboration with the Texas Biomedical Research Institute in San Antonio, Texas using advanced methods of analysis to find new, less easily detected but more powerful genes believed responsible for AMD. Casey’s extensive collection of large families with multiple members with AMD will be the focus of much of the research.

“This funding award by the federal government reflects the accomplishments of our work over the years and along with generous philanthropic support, will allow us to move ahead to the next generation of genetic research, using the most innovative tools and techniques available,” says Michael Klein, M.D., principal investigator of the grant, and director of the Macular Degeneration Center. Study coordinator is Jennifer Maykoski.

For over a decade, scientists at the Macular Degeneration Center have been collecting and analyzing data from thousands of study patients in the Genetics of Age-Related Macular Degeneration Study. During this time, Casey scientists have made several discoveries, beginning with the first published study in 1998 finding a genetic link to the development of AMD through the analysis of a large AMD family in Oregon.

Working often in collaboration with other major international genetic centers, several new AMD genes have been discovered and genetic information has been used to help predict disease progression and an individual’s response to preventive measures and treatments.

“What’s helped make our genetic study so successful is the cooperation and dedication of the thousands of patients who have contributed DNA samples and other health information; the hard work of Casey investigators and staff; and the continued support from generous donors who believe so strongly in our work,” says Dr. Klein.

“[This funding award] reflects the accomplishments of our work and along with philanthropic support, will allow us to move ahead to the next generation of genetic research.”
They came from the Cayman Islands and just a few blocks down the street. Some were newly diagnosed while others have been living with vision impairment for many years. But all were eager to learn, find support and get inspiration at the seventh Macular Degeneration and Low Vision Expo held last October in Northeast Portland.

Sponsored by Casey Eye Institute’s Vision Rehabilitation Center and Macular Degeneration Center, the expo is specifically designed for people with age-related macular degeneration (AMD) and other conditions that cause vision loss, making it one of the few events of its kind and size in the U.S. and OHSU’s largest public education program. Nearly 1,000 participants attended the expo, which was chaired by John Boyer, O.D., director of the Vision Rehabilitation Center. The expo included presentations by Casey faculty and guest speaker Bill Takeshita, O.D., along with breakout sessions led by instructors from the Oregon Commission for the Blind. Twenty-two exhibitors — ranging from vision aid companies to non-profit agencies — were also on hand to demonstrate the latest assistive devices and technology and to raise awareness about services and programs for people with vision impairment.

“I found this to be a wonderful event. It made me feel not so terribly isolated,” commented one attendee. Said another, “What a power packed day! My daughter is inspired to help me learn to use some of this equipment and to implement these suggestions.”

“Dr. Bill was amazing! My husband has dry AMD and Dr. Bill’s positive attitude was very encouraging,” a third noted.

The event’s highlights included:

- **An update on treatment and advances for wet and dry AMD** presented by Michael Klein, M.D., director of the Macular Degeneration Center. Topics covered included new therapies for wet AMD and research progress in treating the dry form; progress in the development of drug delivery systems; an overview of current prevention strategies, and advances in genetics and their applications for people with AMD.

- **A presentation on reading, driving and living fully with vision loss** by Grace Tran, O.D., a vision rehabilitation specialist at Casey. Emphasizing that all patients are unique, she addressed strategies to enhance daily living, such as the use of visual aids, controlling glare and increasing contrast. She also discussed Oregon’s driving laws and bioptic telescopic lenses.

- **Bill Takeshita, O.D.’s moving account** of losing his eyesight at the height of his career as a low vision optometrist (see page 7).

- **A session on new technologies for reading and communicating** led by Richard Turner from the Oregon Commission for the Blind. Apple products, such as the iPhone and iPad, are “truly amazing,” he said, allowing print disabled people to schedule appointments, dictate emails and notes, and handle many other tasks easily.

- **A session on getting around safely and independently** presented by Carolyn Briggs from the Oregon Commission for the Blind. Participants learned about different types of white canes and how best to use them at home and on the street.
The 2011 Macular Degeneration and Low Vision Expo was made possible by:

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Board Members Extend Helping Hand — Locally and Globally

For John and Joy Flaxel, giving back is second nature. Throughout his years as an ophthalmologist on the Southern Oregon Coast, Dr. Flaxel shared his time, knowledge and skills on numerous medical missions to Ecuador, often accompanied by Mrs. Flaxel. The couple, who serve on the Community Advisory Board of the Macular Degeneration Center, are parents of Dr. Christina Flaxel, a retina specialist at Casey Eye Institute.

Volunteering in Ecuador “has been a very rewarding and gratifying experience,” says Dr. Flaxel, who estimates he performed hundreds of cataract surgeries and thousands of eye exams while serving on missions sponsored by Rotary International. Some patients walked for days just to reach the clinic.

“I loved it. We met so many wonderful people,” adds Mrs. Flaxel. For many patients, surgery restored eyesight that had been lost when their cataracts became too advanced. “Patients I helped the year before would come up and thank me,” says Dr. Flaxel, adding with a chuckle that he once operated on his own driver.

Now retired and living in Portland, the Flaxels continue to make a difference in the lives of people here and abroad. As advisory board members of the Macular Degeneration Center, they provide valuable feedback about the center’s activities and enjoy helping out at the Macular Degeneration and Low Vision Expo.

“It is a great pleasure and an honor to have John and Joy Flaxel involved in the activities of the Center. Throughout his long and productive career, John was widely recognized as an outstanding clinician as well as a highly respected leader in ophthalmology and all of medicine. We feel very fortunate that he and Joy have chosen to be a part of our program.”

Dr. Flaxel also volunteers with Casey’s Vision Screening Van, which provides eye exams to medically needy Oregonians. And he and his wife continue to raise funds for and donate equipment to eye clinics, hospitals and orphanages in Ecuador and elsewhere.

Dr. Flaxel, who began his ophthalmology career at OHSU in 1969, remembers when little could be done to treat age-related macular degeneration. “Laser was all there was,” he recalls, noting that injections of newly developed medications can preserve and even improve vision in many cases of wet AMD and certain nutritional supplements may help slow the progression of the disease.
After Losing Sight, Optometrist Gains New Perspective

Speaker’s Honest Account at Low Vision Expo Strikes Chord
As long as he could remember, Bill Takeshita, O.D., wanted to be an eye doctor. Growing up, he was a poor athlete and had difficulty in school until a school nurse told him he needed eyeglasses. After getting fitted, “I couldn’t believe how the world looked. It changed my life,” he told a packed hotel ballroom at Casey Eye Institute’s Macular Degeneration and Low Vision Expo last October. “I was no longer picked last for baseball, just second last,” he added, laughing.

That childhood experience inspired him to help others affected by vision problems and he decided to pursue a career as a vision rehabilitation optometrist. By the 1990s, the young optometrist, who goes by “Dr. Bill,” had a happy family life and thriving practice in Los Angeles, where he developed one of the largest pediatric low vision clinics in the West. He was so engrossed in his profession that he often worked seven days a week, helping children and adults with severe vision impairment.

“I thought I was hot stuff,” recalled Dr. Bill, whose patients included athletes and celebrities. “Life was everything I wanted it to be.”

But when a rare retinal disorder began robbing him of his eyesight, life as he knew it came crashing down. At first, he tried alternative treatments to stall the disease, including Chinese herbs, intravenous vitamin therapy and acupuncture. As his vision worsened, he grew angry and became isolated. “Dr. Bill became Dr. Bitter,” he said. “I didn’t want to see patients or friends and didn’t play with my kids as much. My anger was affecting my marriage. I kept thinking, ‘How unfair this is’ and ‘Why did it happen to me?’ Life became terrible.”

Many audience members nodded in acknowledgment as Dr. Bill, the featured speaker at the expo, recounted his journey into blindness, detailing the feelings of anger, loneliness and depression that often surface when eyesight diminishes. Coming from an expert in vision loss, his story resonated deeply with those affected by age-related macular degeneration (AMD) and other eye conditions.

Nearly a year after his diagnosis, Dr. Bill made the difficult decision to retire from his practice. “It was the hardest thing,” he said, adding that life seemed worthless.

But his outlook began to change after his beloved older brother suffered a massive heart attack and urged him not to give up. “My brother valued life so much and lived each moment to its fullest. I decided to do the same.”

(Continued on page 8)
Optometrist Gains New Perspective  *(Continued from page 7)*

and to make a commitment to live life as a visually impaired person,” said Dr. Bill, whose brother died before he could get a heart transplant.

“I started to wear amber glasses, use magnifiers and other visual aids and invested in a video magnifier,” he said. He also learned to use Braille and devices that talk.

But he hated the idea of a cane. “I was embarrassed,” he admitted. Over time, he got over his reluctance and was pleasantly surprised to discover how useful a white cane can be for mobility and safety, and to let people know you are sight-impaired. Using one for the first time in the airport in Hawaii, “it was amazing — it was like Moses parting the sea,” he said.

Visual aids, he said, can help you continue your activities and even do things better. “I read more efficiently now because I can listen to audio books while on the treadmill,” he said.

Innovations in lighting, video magnifiers and other aids have made a huge impact, helping people with vision loss continue their day-to-day activities.

“This is the best time in history to be visually impaired,” he told the audience, concluding his talk to thunderous applause and a standing ovation. “There is so much hope for the future.”